Workflow Management for Multiple Sclerosis Patients: IT and Organization

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Abstract

Patients with Multiple Sclerosis (MS) visit various healthcare providers during the course of their disease. It was suggested that IT might help to orchestrate their care provision. We have applied the USE IT-tool to get insight in the relevant problems, solutions and constraints of the MS-care and the MS care providers both in the organizational and the information technological area. There is hardly a chain of healthcare, but rather, a network in which informal communication plays an important role. This informal network worked reasonably effective, but inefficient and slow. The patient himself plays a key-role in information exchange between care-providers. Many providers were unaware of the services that other healthcare providers could give in general or did provide to a specific patient. MS patients-count is only small for most care providers. None of the interviewed patients mentioned a lack of contacts between care-providers as a problem. They thought that lack of experience caused their major problems: insufficient and inadequate care. To improve care, we proposed a solution that combines a "short MS-protocol", the introduction of a central coordinator of care and a Patient Relation Management (PRM) System. This is a simple web-based application that is based on agreement by the caregivers that supports routing, tracking and tracing of a MS patient and supplies the caregivers with professional guidelines, as written down in the protocol. It is likely that we would have suggested a far more complicated ICT solution if we had only analyzed the MS-care process as such, without specific consideration of the USE IT dimensions.

1. Introduction

Multiple Sclerosis (MS) is a disease that affects the central nervous system. Due to causes that are not entirely understood, the sheaths of the nerves change which reduces the ability to transmit signals. Patients may suffer from tiredness, have difficulty to move, may have reduced sight and an range of other problems. There is no cure available for MS; treatment may be able to relieve the patients' symptoms, and by that extend the period that the patient is able to function independently.

Patients with Multiple Sclerosis (MS) visit various healthcare providers during the course of their disease. A general practitioner might be their first contact, but, as the disease progresses, a neurologist, urologist, rehabilitation hospital, homecare, home-adaptation and many other types of support are normally needed. In a perfect world, all these forms of care are delivered in an orchestrated way. However, reality is different. Each provider uses his or her own patient records and working method. The patient needs to be self-managing. A rehabilitation hospital asked us to study the health care chain of MS in a Dutch region that serves about 500 MS patients and includes three large hospitals (with a total of about 1800 beds). The challenge of this research-project was to find a solution that is locally, practically applicable and that can serve as a base for a more general, broader solution on the same time. This challenge is represented in the two research-questions, which are formulated as follows:

- In what way does an improvement of the information-services in the healthcare chain contribute to the improvement of the quality of care for patients with multiple sclerosis?
- How should a solution look like that solves the local problem but that also aligns with knowledge and standards on EPR and serves as a first step or building block of an EPR?

So, could IT help to coordinate the workflow for MS

patients?

2. Research approach

Workflow management in Healthcare settings is not an easy task. Organizations that work for the same patient may have different goals or policies use different standards and may appreciate their autonomy. Also, redesign of the workflow may be needed to enable workflow-management [1]. In practice, other factors that are even more down-to-earth may inhibit workflow-management. For example, an insufficient existing IT structure or other problems that exist, which are unrelated to the workflow-problems that are considered, may be so dominant that healthcare workers are not prepared to generate time, effort or money to solve these problems.

Previous research [2] made us realize that it is important to consider the problems and possible solutions to the proposed theme of Workflow Management by Use of IT for the MS Healthcare chain in the context of other problems in the provision of healthcare to MS patients. Also, the study needed to take into account that professionals have different goals, working methods and backgrounds. For some, MS patients are an important target group; others may use the most of their time and effort for other patient groups. So, it was decided to interview 17 care providers, which are part of the MS-care chain in Twente, a Dutch region. Each interview took about 1 1/2 hr. Also 6 of the approximately 500 patients were interviewed to get an impression of how they experienced the provided care. These interviews took about one hour. Before we started the interviews, formal documents on the organization of the relation between caregivers were studied as well as general literature on MS.

Regarding the interviews with the care providers, we reviewed papers on tools to reveal the user's requirements or tools to stimulate user participation in the development of information systems in health care have been published the previous years, e.g. [3] [4] [5] [6]. These tools usually focus on a fit between the developed system and the user on one aspect of innovation-diffusion. The USE IT-tool builds on a large number of such publications and comprises four diffusion aspects: relevance, resistance, requirements and resources [7] [8] [9] [10]. This includes literature on success factors for Electronic Patient Records (EPR). These factors of success are: relevant to the end-user, integrated and complete patient data, available to all caregivers, and containing active elements. To meet these four criteria of success an EPR must cross the borders of its orientation [11]. The importance of a well-designed architecture and the use of standards are stressed by Van Ginneken [12] and Stegwee [13]. Although some promising developments exist, it is also clear that such an EPR will not be available in a short time to every local caregiver. The E IT tool helps to get insight in the nature and relevance of problems and of possible solutions, and thus consider all of the above-mentioned aspects of the problem. It considers constraints and prerequisites, which are particularly relevant when resources are limited and choices have to be made as to which problems will be solved and which will not. Proposed solutions that come to mind after the analysis can be organizational changes, IT-related changes or both.

Table 1 shows the measured dimensions and related sub-dimensions, which are measured using the USE IT-tool[1] for structured interviews.

Table 1- USE IT-model

Dimensions	**Sub-dimensions**
Relevance	Macrorelevance • Relative advantage • Compatibility Microrelevance • Here-and-now relevance
Resistance	Opportunity to change Ability to change Attitude to IT
Requirements	Strategic general requirements Functional requirements
Resources	Material Immaterial

For the interviews with patients, we used a much shorter questionnaire (see appendix 1).

3. Result of the MS-healthcare chain research

Based on the formal documents we studied, we were able to model the formal referral model through the MS-chain (figure 1) [14]. Figure 2 shows contacts related to the patient, as reported by the caregivers.

[1] The USE IT-tool is available via the Internet.

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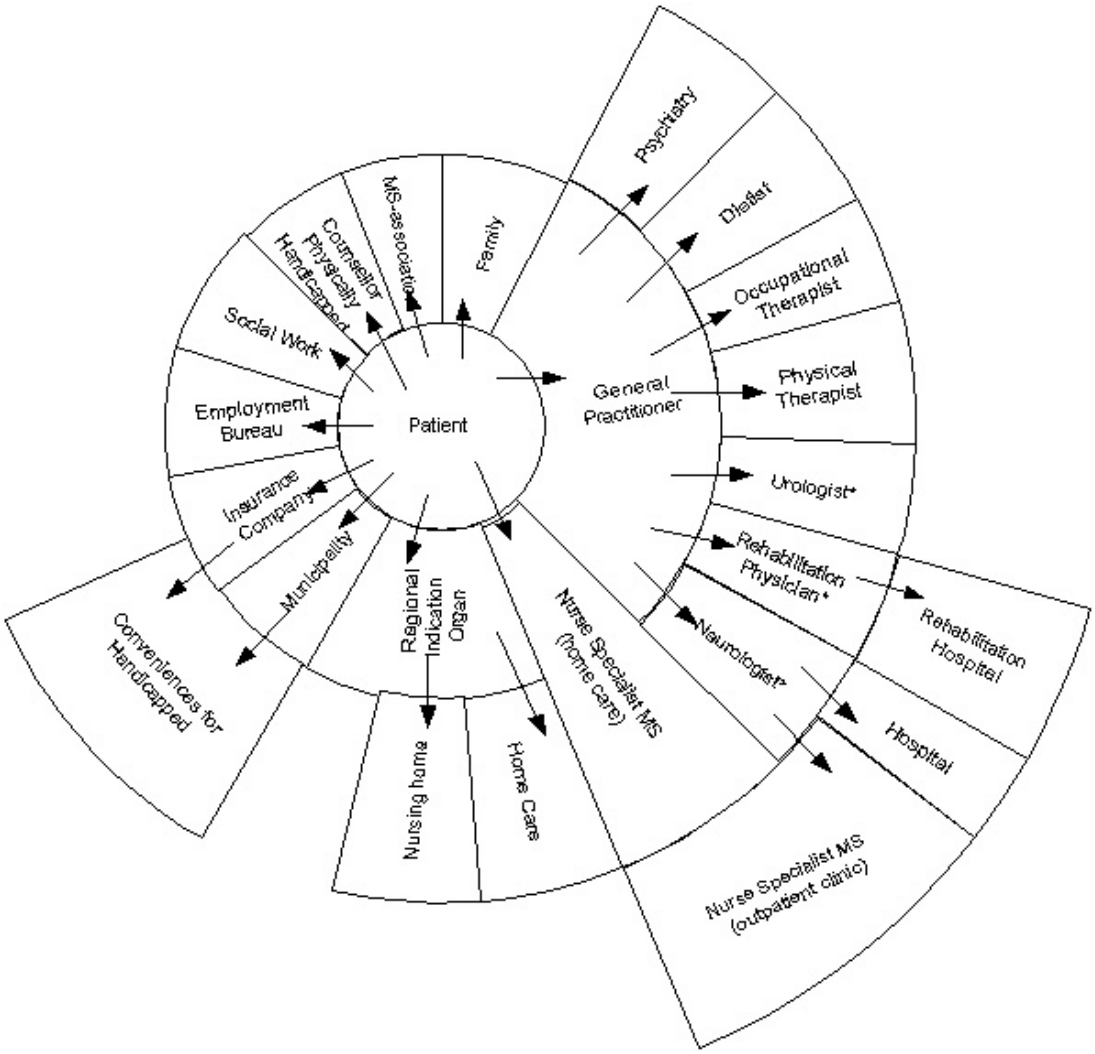

Figure 1: The formal referral model of the MS healthcare chain

Referral takes place from the inside to the outside. The patient does not need any official referral to go to the GP, RIO, municipality, insurance company, employment bureau, social work, counsellor PH and the MS-association. Adapted conveniences are available through the healthcare insurance company or the municipality. The Regional Indication Office (RIO) decides on admission to a nursing home or whether the patient is eligible to home care. The latter may concern nursing or general care. Advice, information or instruction by homecare is available without intervention of the primary physician or the RIO. This is the type of homecare that is given by a nurse specialist that is specialized in MS patients. Referral by the GP is needed to get access to treatment by other physicians or paramedics. The star in the boxes for the physicians indicates that physicians may generate referrals to the same paramedical healthcare workers as the GP. The rehabilitation physician serves as the gate to other healthcare providers in the rehabilitation hospital. The neurologist decides on hospitalization and is also the person who refers to a nursing specialist in the outpatient clinic. In one part of the area that was studied these two specialized nurses are in fact the same person.

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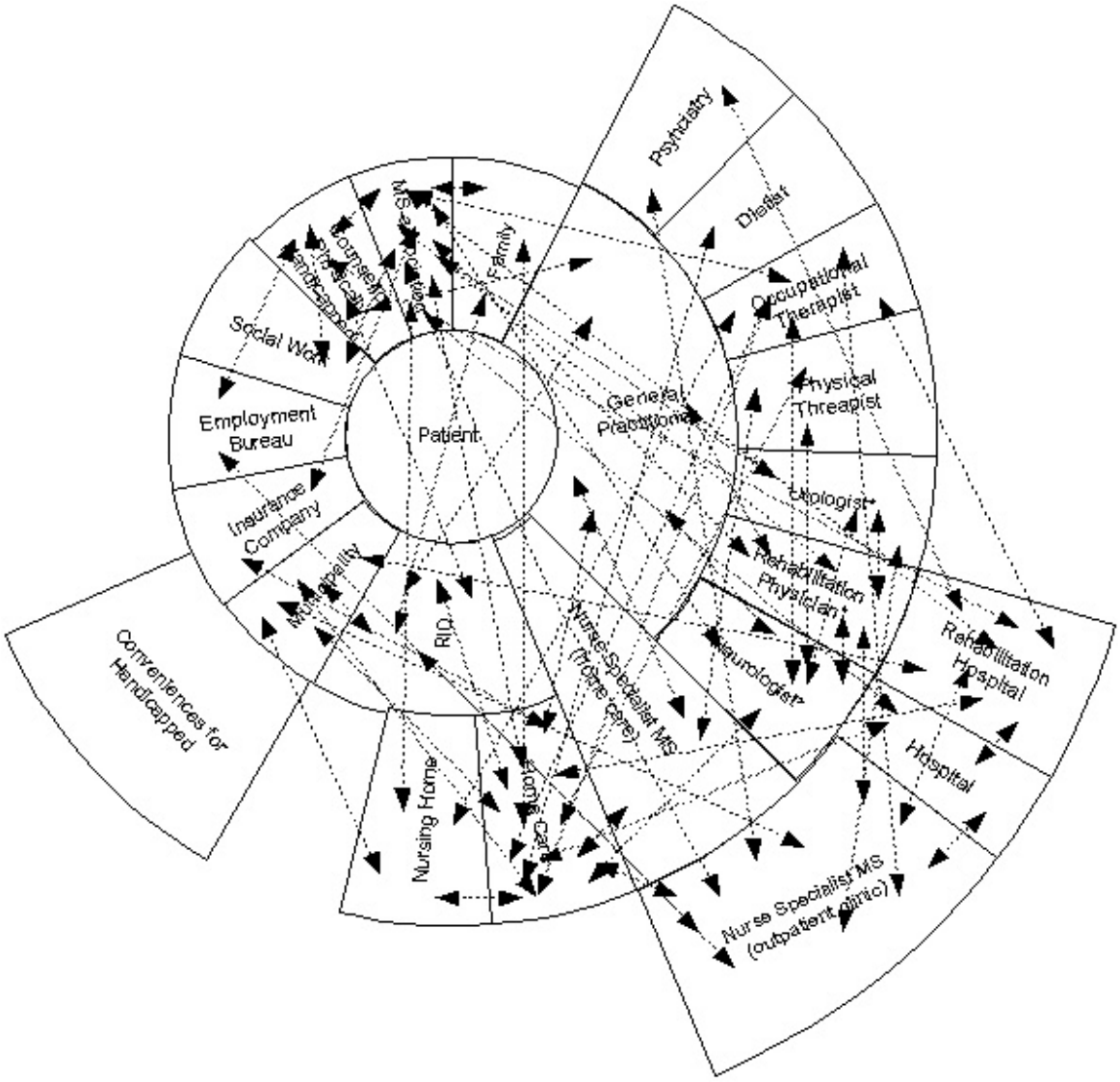

Figure 2: Contacts related to the patient, as reported by the caregivers.

This figure only depicts relations that are not based on formal referral. Also, the contact between the patient and caregivers is not shown in the figure.

This figure only depicts relations that are not based on formal referral. Table 2 is a cross-table of information flows between the parties involved.. The first conclusion is that there is hardly a chain of healthcare, rather, a complex network with many cross-relations. Patient-flow or workflow was not organized for the specific patient group.

Two coordination mechanisms could be found: the official referral system and informal communication (mutual adjustment). The formal communication did not suffice; it did not cover all the information needs. Also, the formal key-role is destined for the GP, who is –in practice- too busy with other tasks to fulfill his role as coordinator of care. The informal network between care providers seemed reasonably effective, but inefficient and often slow. Within this network, we found handovers between caregivers that were executed by the patient himself. Six care providers indicated that the patient is the major source of

information. It is not a great surprise that patients and caregivers sometimes get lost or stuck in this spider-web, although patients felt these problems to a lesser extent than caregivers. All patient records are local. All electronic records only contain administrative information, no care-related information.

Table 2. Patient-related contacts between care providers.
Horizontally: positions or institutions that were interviewed. Vertically: positions or institutions with whom they have patient-related contacts marked with number "1". Grey boxes indicate that formal referral is possible.

Interviewed (number) Reported contacts and referrals	MS-association (2)	Nurse-specialist MS (2)	Rehabilitation-Hospital (2)	Neurologist	Home-care (2)	Regional Indication Organ	Social Counsellor Physically Handicapped	Municipality (Conveniences)	Occupational Therapist	Nursing-home	*total*
MS-association	1	1		1			1				*4*
Nurse-specialist MS	1				1			1	1		*4*
Rehabilitation Hospital	1	1	1	1	1		1	1	1	1	*9*
Neurologist	1	1	1						1	1	*5*
Home-care	1	1	1		1	1	1		1		*7*
Psychiatry		1	1								*2*
Regional Indication Organ	1	1			1		1	1		1	*6*
Insurance company	1										*1*
Municipality (Conveniences)	1				1	1					*3*
Occupational Therapist	1	1			1						*3*
Nursing-home		1				1		1	1		*5*
Physical Therapist		1	1	1	1						*4*
General Practitioner		1	1	1	1	1	1			1	*7*
Family	1	1			1	1			1		*5*
Hospital ward	1		1		1						*2*
Urologist	1	1	1	1							*4*
Dietist					1						*1*
Social Work	1						1				*2*
Counsellor Physically Handicapped		1									*1*
Employment Bureau		1					1				*2*
Others	1					2	5	1			*10*
total	*15*	*14*	*8*	*5*	*11*	*7*	*12*	*5*	*6*	*4*	*87*

Not all healthcare providers were aware of the service that other caregivers could provide in general and do provide for a specific patient.

The USE IT-tool also made clear that MS-care is not very relevant for most caregivers. That is to say, caregivers have high compassion to MS-patients, but most caregivers only occasionally saw MS-patients. The only notable exceptions to this were the specialized MS-nurse and some of caregivers in the rehabilitation hospital. But even in this group, the maximum percentage of patient-time spend on MS-patients does not exceed 40%. The neurologist in the largest hospital in the area is specialized in MS. However, also for him, MS patients create just above 10% of his work.

Because of this infrequent contact with MS-patient

the knowledge of caregivers about MS-care seemed to be lacking at times. All interviewed patients said this lack of knowledge was the cause of one of the major problem they reported: incidents of insufficient and inadequate care. It should be noted that none of the care providers mentioned this theme. The patients had little complaints about the low level of contacts that have been noticed to exist between caregivers. The relation with each caregiver may continue for years, so, they saw little need for intensive contact between these caregivers. All in all, patients were satisfied about the provided care, although they consider it very fatiguing to arrange new facilities or access to "new" caregivers. They say a very pro-active role of the patient is needed. This was especially bothersome because MS patients get less energetic when the disease develops. Table 3 gives an overview of the bottlenecks and disturbances.

Table 3. Bottlenecks and disturbances

Bottlenecks and disturbances	**total**
Waiting-lists for conveniences, nursing home and psychologist	9
Coordination, communication, working according to plan	9
Double work, fragmentation and lack of survey, due to lack of coordination	5
Care providers do not know each others possibilities in care	5
Care providers do not know about each others progress according to the patient	5
Limited time for providing care	4
Insurance companies, municipality and GP are unfamiliar with MS	3
Care provider only listens to the patient and ignores advise of other care providers	3
The patient does not have survey of who is treating him	2
The MS-association behaves as being a professional care provider	2
Patients wait too long before requesting a convenience	2
General Practitioner should be coordinator, not just referrer	2

4. Constraints and prerequisites

There is no regional Electronic Patient Record or likewise IT facility in the area studied that could serve as a basis for solutions. Some caregivers use electronic records, but these systems are often used for administration purposes only and limited to the use in one institution. Almost all caregivers have (or would have in short notice) access to e-mail or the Internet.

Since the relevance of MS-care is only high to a few caregivers, most caregivers could not spend much time and effort in implementing a specific solution for MS-care. They fear to be loaded with separate solutions for every separate chronic disease. This means that solution to the problems in MS-care has to meet the following constraints: 1. No isolated solution for MS-care: a specific solution must be expandable for other diseases, 2. Implementation and maintenance must take very little effort and costs and 3. The solution must adhere to the present conditions.

5. Patient Relation Management

Several interviewed caregivers considered a regional EPR as *the* solution to the problems in MS-care, although many did not consider this realistic. The main benefits of an EPR would be to know who is involved with what patient and to have access to the necessary information without being dependent of other caregivers such as the GP as 'pass on-desk' of information. An EPR could help to make clear amongst care providers what each of them does for an individual patient. However, both the realization and the use of a regional EPR demand much more effort, time and expenses than is available for improving MS-care. Also, the condition that MS-patients make up a small percentage of the total patient population for most healthcare professionals is unaffected. As a consequence, patients will retain the problem that healthcare providers do not give adequate care nor is it sure that referral patterns will improve.

That is why we suggest a solution that combines three elements. First, we suggest to make a "short MS protocol" that lists the options of care that each of the care providers offers. Preferably, agreement has to be accomplished about the routing of a patient through the healthcare chain when the patient is diagnosed MS. Secondly, we suggest that the nurse specialist should play a central role as coordinator of care. But to fulfill this coordinating role support is needed. So, the third element is to build a Patient Relation Management (PRM) system. This PRM consists of a web-based patient routing system, based on an agreement of the caregivers in the region on patient-flow (cf. the short protocol). When a patient is reported to the system a message will be send automatically to those caregivers, which should be informed. The information in the

system comprises the names of the reported patients and the names and functions of the caregivers that are or have been involved with the treatment of the patient and the likely next steps (caregivers) in the treatment. PRM does not contain medical data of the patient and does not substitute the patient records from the various caregivers. The system is part of a website that contains general information on MS and medical guidelines for caregivers.

PRM supports the organizational solution of the main problem of the caregivers by making the agreed guidelines and patient-flow available, easy to maintain and enriching it with knowledge caregivers need. They know to whom they should refer the patient and which caregivers can be asked for more information about the patient. We think that the effort it takes to report a patient to the system is rewarded by the more efficient communication that results and the information the caregiver can retrieve about the treatment of the patient. Many caregivers, who seldom see an MS-patient, lack this knowledge.

Eventually, this PRM could serve as a first step to accomplish a regional EPR. During the interviews, it became clear that other chronic diseases have similar problems [15]. So, the use of the PRM could be expanded to health care chains for chronic care.

To be a building block of an EPR, PRM must be designed and built according international standards. Its architecture has to be open and transparent to make linking possible to different information systems, such as an EPR or a HIS in different institutions. Since PRM contains information of patients and caregivers, security is important.

6. Discussion

This paper gave an example of a thorough analysis of problems of workflow management in a healthcare setting. The solution we suggest is specifically geared for this type of care (i.e. network rather than chain, chronic, low relevance for most care providers). It is a complex solution in the sense that it combines the creation of a protocol, with the introduction of a new organization form (the coordinator) and with the introduction of the PRM. It is a simple solution in the sense that none of these three elements is on itself complex or difficult to realize. Each of these three elements is equally important, as only the introduction of all three elements will lead to improved workflow management. When we particularly focus on the role of IT for the workflow management in the healthcare network, it is once again an essential enabler for new organizational forms. We have tried to find solutions that were entirely organizational or IT-related, but we have not managed to design one that could work. So, in line with what many thought when we started the project, IT was essential to create a solution, although it could not bring a solution on its own.

A major advantage of PRM is that it is a simple, inexpensive solution to present problems experienced by local caregivers, which does not create a new island of automation. Neither does PRM prohibit the development and implementation of an EPR. On the contrary we think that PRM can pave its way. PRM stems from the care process orientation, but could also be applied in the medical technology or administration orientation [9]. To be successful, an EPR must be relevant to the end-user, must present all patient data in an integrated way, must be available to all relevant caregivers and contain active elements. To meet these criteria an EPR must cross the borders of its orientation. PRM does not offer all this. In a sense, it fails on the second EPR criterion and its activity is limited to notifying caregivers that a patient, whom should be seen, is reported. Further analysis would be needed after the introduction of PRM to clarify which design of a regional EPR could have added value.

7. Conclusion

Existing tools to identify processes and interviews with future users are common ways to map the conditions where IT solutions can be applied in healthcare. We learned from this research that the USE IT analysis of the characteristics of the end-user helps to provide a more appropriate picture of the problem and the constraints and prerequisites for solving it. It is likely that we would have suggested a far more complicated ICT solution if we had only analyzed the MS-care process as such, without specific consideration of the USE IT dimensions. The USE IT analysis helped us to balance the breadth of the proposed solution with the nature of the situation the future users of the system are in. The use of IT does not automatically mean that an EPR is needed [16].

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Appendix 1. USE IT-protocol for patients

MS-patiënt	
Pat.1	Would you be so kind to describe the course of your illness to me and especially your route through healthcare?
Pat.2	What care do you receive at the moment?
Pat.3	Do you experience bottlenecks in the care delivered?
Pat.4	What role does MS play in your life?
Pat.5	How do you experience the cooperation between health care providers or institutions?
Pat.6	How do you experience the supply of information on MS?
Pat.7	How do you experience the way care providers deal with the information about you?